COMMITMENT
INTEGRITY
LEADERSHIP

August 30, 2022
Report 2021-120

FACT SHEET

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In-Home Respite Services

The Department of Developmental Services Has Not Adequately Reduced Barriers to Some Families' Use of In-Home Respite Services

Background

The Department of Developmental Services (DDS) oversees the coordination and delivery of the care and treatment of individuals with intellectual and developmental disabilities. One of the services DDS oversees is the State's in-home respite services program (respite services), which provides temporary care and supervision to those with such disabilities who reside with family members. The State's 21 contracted regional centers coordinate respite services in their respective geographical areas. Our audit of four of these regional centers—Golden Gate, Inland, San Andreas, and San Diego—found that DDS has not taken adequate action to reduce barriers to some families' access to these critical respite services.

Key Findings

- Among the barriers that prevented some families from accessing respite services was a lack of available respite workers and difficulty finding respite workers who speak the family's language.
  - » Although DDS ensures that regional centers obtain feedback to identify disparities in using respite services, it has not ensured that regional centers adequately act to reduce those disparities.
- DDS has not done enough to ensure that regional centers allow families to receive the full number of allowable respite service hours.
  - » Years after the repeal of a state law limiting respite hours, inadequate DDS oversight has allowed some regional centers to maintain policies that impose limits on respite services.
- DDS has not taken adequate action to ensure that all families have access to one respite service option that could help reduce some of the barriers to accessing services.
  - » Of the 21 regional centers in the State, 13 seldom or never offer this potentially beneficial service option.

Key Recommendations

The Legislature should do the following:

- Require DDS to submit annually a plan outlining the specific, measurable actions it will take to reduce barriers and disparities in the use of in-home respite services.
- Require DDS to regularly adjust reimbursement rates to attract an adequate number of respite workers.
- Require regional centers to identify measurable actions to reduce barriers and disparities and require DDS to annually follow up with regional centers on the status of these actions.

DDS should do the following:

- Perform a more comprehensive analysis on the data it collects from regional centers to identify disparities in the use of respite services and take action to address those disparities.
- Review regional center policies to ensure that they no longer contain hourly limits to respite care.
- Develop standard outreach materials about different service options, require regional centers to train staff on the benefits of each option, and require regional centers to plan for an adequate number of service providers for each service option.

Some of the Barriers to Accessing Respite Services Include . . .

LACK OF AVAILABLE WORKERS
In some areas, there is an insufficient supply of respite workers because of low reimbursement rates or scheduling difficulties.

INCOMPATIBILITY
Some families struggle to find respite workers with whom they are comfortable, personally or culturally.

LANGUAGE GAPS
Families have difficulty finding respite workers who speak their language.

SHORTAGE OF SPECIALIZED WORKERS
There is a shortage of respite workers trained to work with particular needs, including specific behaviors.

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August 30, 2022
2021-120

The Governor of California
President pro Tempore of the Senate
Speaker of the Assembly
State Capitol
Sacramento, California 95814

Dear Governor and Legislative Leaders:

My office conducted an audit of the Department of Developmental Services' (DDS) oversight of the State's in-home respite services program (respite services), which provides temporary care and supervision to individuals with intellectual and developmental disabilities who reside with family members. The following report details our conclusion that DDS has not adequately reduced barriers to some families' use of the respite services that they were authorized to receive.

Among the barriers that prevented some families from accessing respite services was a lack of available respite workers. Although DDS ensures that regional centers, which administer respite services, obtain feedback from stakeholders to identify disparities in families' use of regional center services, DDS has not made sure that regional centers adequately act on that information to reduce those disparities.

DDS also has not done enough to ensure that regional centers allow families to receive the full number of allowable respite service hours. Although state law used to limit the number of respite service hours that a family could receive per quarter, that law was repealed in 2018. Nevertheless, we found that some regional centers still have policies that impose limits.

Although one of DDS's service delivery options for respite service could help more families get the services they need, DDS has not ensured that regional centers offer it to families. In fact, at 13 of the 21 regional centers in California, very few families use this service delivery option, which can allow families to hire their own respite worker with whom they are comfortable and who speaks their language. Two of the four regional centers we reviewed did not ensure that this option was available to families.

Respectfully submitted,

MICHAEL S. TILDEN, CPA
Acting California State Auditor

Selected Abbreviations Used in This Report

DDS	Department of Developmental Services
EOR	Employer-of-Record
FMS	Financial Management Services
Lanterman Act	Lanterman Developmental Disabilities Services Act

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Summary

The Department of Developmental Services (DDS) oversees the coordination and delivery of the care and treatment of individuals with intellectual and developmental disabilities, whom state law refers to as *consumers*. One of the services DDS oversees is the State's in-home respite services program (respite services), which provides temporary care and supervision to individuals with intellectual and developmental disabilities who reside with family members. The State's 21 contracted regional centers coordinate respite services for consumers in their respective areas. Our audit of four of these regional centers—Golden Gate, Inland, San Andreas, and San Diego—found that DDS has not adequately taken action to reduce barriers to some families' access to respite services.

DDS Has Not Taken Critical Steps to Address Disparities in the Use of In-Home Respite Services

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Some families were not able to access respite services because of barriers such as a lack of available respite workers and difficulty finding respite workers who speak the family's language. Although DDS verifies that regional centers, which administer the in-home respite services program, identify disparities in families' use of regional center services by obtaining feedback from stakeholders, DDS has not ensured that regional centers take adequate actions to reduce these disparities.

Because of DDS's Insufficient Oversight, Some Regional Centers May Impose Inappropriate Limits on Respite Services

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Since the 2018 repeal of a state law limiting the authorization of respite services, DDS has not adequately ensured that regional centers are no longer limiting the number of respite hours a family may receive. In particular, we found that some regional centers still have policies that impose a limit. For example, one regional center's policy states that the regional center may not authorize more than 90 in-home respite hours in a quarter for a consumer. Because DDS does not ensure that regional centers have clear processes or documentation, it cannot determine that they are not inappropriately restricting the number of in-home respite hours made available to families.

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Not All Families Have Sufficient Access to a Potentially Beneficial Respite Service Option

DDS has historically offered three delivery options for access to respite services: the In-Home Respite Service Agency (Agency) option, the Employer-of-Record (EOR) option, and the Financial Management Services (FMS) option. However, very few families use the FMS option, which is also known as Participant-Directed Services, thus missing the benefits that FMS provides, such as hiring their own respite worker with whom they are comfortable and who speaks their language. Even though the FMS option may be the best choice for some families, the regional centers we reviewed have neither adequately informed all families about its existence nor ensured that this option was available to families.

Recommendations

Following are the recommendations we made as a result of our audit. Descriptions of the findings and conclusions that led to these recommendations can be found in the sections of this report.

Legislature

The Legislature should amend state law to require regional centers to include in their annual disparity reports to DDS—which show demographic data about the users of in-home respite services—specific, measurable actions to reduce barriers and disparities in the use of these services. At a minimum, these reports should identify the following:

- Concrete, measurable actions the regional center will take to improve access to in-home respite services.
- Timelines for completing those actions, including specific intervals for periodic updates on progress.
- Specific outcomes the regional center plans to achieve through these actions.

The Legislature should amend state law to require DDS to submit a plan to the Legislature during the annual budget process that outlines the specific and measurable actions it will take to reduce barriers and disparities in the use of in-home respite services.

To ensure that DDS takes adequate actions to verify that regional centers address barriers, the Legislature should amend state law to do the following:

- Require DDS to annually follow up with regional centers by instructing the centers to produce a status report each year on steps they have taken to reduce barriers to using in-home respite services.
- Require corrective actions from regional centers that DDS determines have failed to take sufficient action.

To promote transparency and accountability, the Legislature should require DDS to promulgate regulations establishing a standard method—similar to the assessment tool used by some regional centers—for regional centers to document their rationale for determining the amount of in-home respite hours they authorize.

The Legislature should require DDS to, every two years, determine whether the current reimbursement rates for in-home respite services are sufficient to attract an adequate number of respite workers statewide and to adjust the rates accordingly.

The Legislature should require DDS to, every two years, evaluate, develop, and implement incentives, as necessary, to attract in-home respite workers with skills and abilities that can reduce barriers, including the shortage of respite workers who are bilingual or who are trained in dealing with specific behaviors.

DDS

To ensure that it has sufficient data to better identify usage barriers and disparities, DDS should update its in-home respite data by February 2023 to periodically track the amount of respite hours authorized and used by each regional center, and the usage of each service delivery option (Agency, EOR, or FMS). DDS should use this information and the data it already collects from the regional centers to identify potential limits, trends, and disparities related to in-home respite services. DDS should, at a minimum, analyze the usage of and authorization for in-home respite services across the categories we list in the report. That analysis should identify any disparities statewide, at individual regional centers, or among regional centers. If DDS identifies problematic disparities that suggest barriers to the use of in-home respite services, then it should take action to address them. For example, DDS should direct regional centers with low FMS usage to conduct additional outreach to ensure that families are aware of the benefits of this option.

DDS should review the policies of all 21 regional centers by October 2022 to ensure that they do not contain provisions imposing overall limits on the amount of in-home respite service hours authorized for families to receive each quarter and require revisions as necessary.

DDS should develop standard outreach materials by February 2023 that present key information about each respite service delivery option, including a description of each option and its benefits and drawbacks. It should provide these outreach materials in multiple languages on its website and to all regional centers to include on their websites and disseminate to all of the families that use centers' services so that they have the knowledge and opportunity to select the option that best fits their needs.

DDS should amend its contracts with the 21 regional centers by February 2023 to require all regional centers to have a plan for ensuring that they have an adequate number of service providers for all in-home respite service delivery options, including the FMS option.

DDS should amend its contracts with the 21 regional centers by February 2023 to direct them to train their service coordinators to explain the benefits of each of the in-home respite service delivery options so that families can determine which option will work best for them.

Agency Comments

DDS agreed with our recommendation for developing outreach materials and partially agreed with our other recommendations.

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Introduction

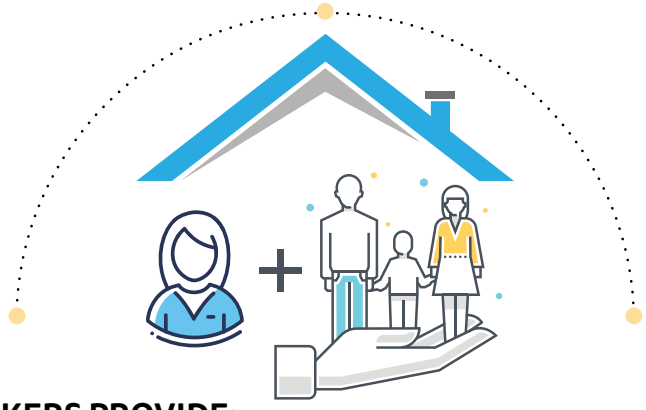
Background

In-home respite services are intermittent or regularly scheduled temporary, nonmedical care and supervision provided in the home for individuals with intellectual and developmental disabilities who reside with their family members. Respite services relieve family members (caregivers) from the constantly demanding responsibility of caring for individuals with intellectual and developmental disabilities, whom state law refers to as *consumers*. Developmental disabilities include intellectual disabilities, cerebral palsy, epilepsy, autism, and other disabling conditions closely related to an intellectual disability. In-home respite services are designed to protect the consumer's safety and to address basic self-help needs and other activities that would ordinarily be performed by the family members, as shown in Figure 1. In-home respite services are critical to families that care for loved ones who are consumers because these services can help improve family relationships by providing primary caregivers relief from their duties. Specifically, these services can reduce stress between a caregiver and a consumer.

Figure 1
In-Home Respite Services Provide Short-Term Relief to Family Members

In-home respite is temporary care and supervision provided in the home of a consumer and offers caregivers (usually parents) relief from the stress of caring for a family member with elevated needs.

In-home respite is designed to help families stay together in their homes.



In-home respite services are provided by approved respite workers to consumers who live at home with their families.

Respite services discussed in this report are short-term, temporary care and supervision and are generally nonmedical in nature.

RESPITE WORKERS PROVIDE:

- Care and supervision to ensure the safety of consumers in the absence of family members.
- Relief for family members from the constant demand of caring for consumers.
- Help with basic needs (such as eating and getting dressed) and other daily activities for the benefit of the consumer that would ordinarily be performed by family members.

Source: State law and DDS service definitions.

Examples of Services and Support That Regional Centers Procure for Consumers

- **Respite Care:** Provides temporary relief for families or caregivers from care needs of consumers.
- **Speech Therapy:** Helps consumers improve communication.
- **Behavior Training:** Addresses consumers' behavioral challenges.
- **Transportation:** Helps consumers access their services or the community.
- **Adult Day Program:** Provides programs for adult consumers to learn new skills, socialize, and have their care needs met.

Source: DDS documentation.

Department of Developmental Services

Since the enactment of the Lanterman Developmental Disabilities Services Act (Lanterman Act) in 1977, the State has accepted responsibility for providing services and support to consumers and their families. Under the Lanterman Act, the Department of Developmental Services (DDS) is responsible for overseeing the coordination and delivery of care and treatment of consumers. As of March 2022, about 380,000 Californians receive services and support through the Lanterman Act.

DDS is responsible for the State's in-home respite services program. DDS contracts with a network of 21 regional centers throughout California to coordinate services for consumers. These regional centers are private, nonprofit corporations that receive funding and oversight from DDS. The regional centers contract with service providers (vendors), such as respite agencies or Financial Management Services (FMS) companies, to provide a variety of services to consumers. The text box lists examples of some of these services. Although in-home respite services make up a small monetary part of the services DDS provides to consumers, they benefit many families. In fiscal year 2021–22, the state budget allocated $6.5 billion to support regional centers statewide. During the same period, DDS budgeted $960 million for in-home respite services. DDS reported that nearly 84,000 family caregivers benefited from respite services during fiscal year 2020–21.

Regional Centers Have Multiple Responsibilities

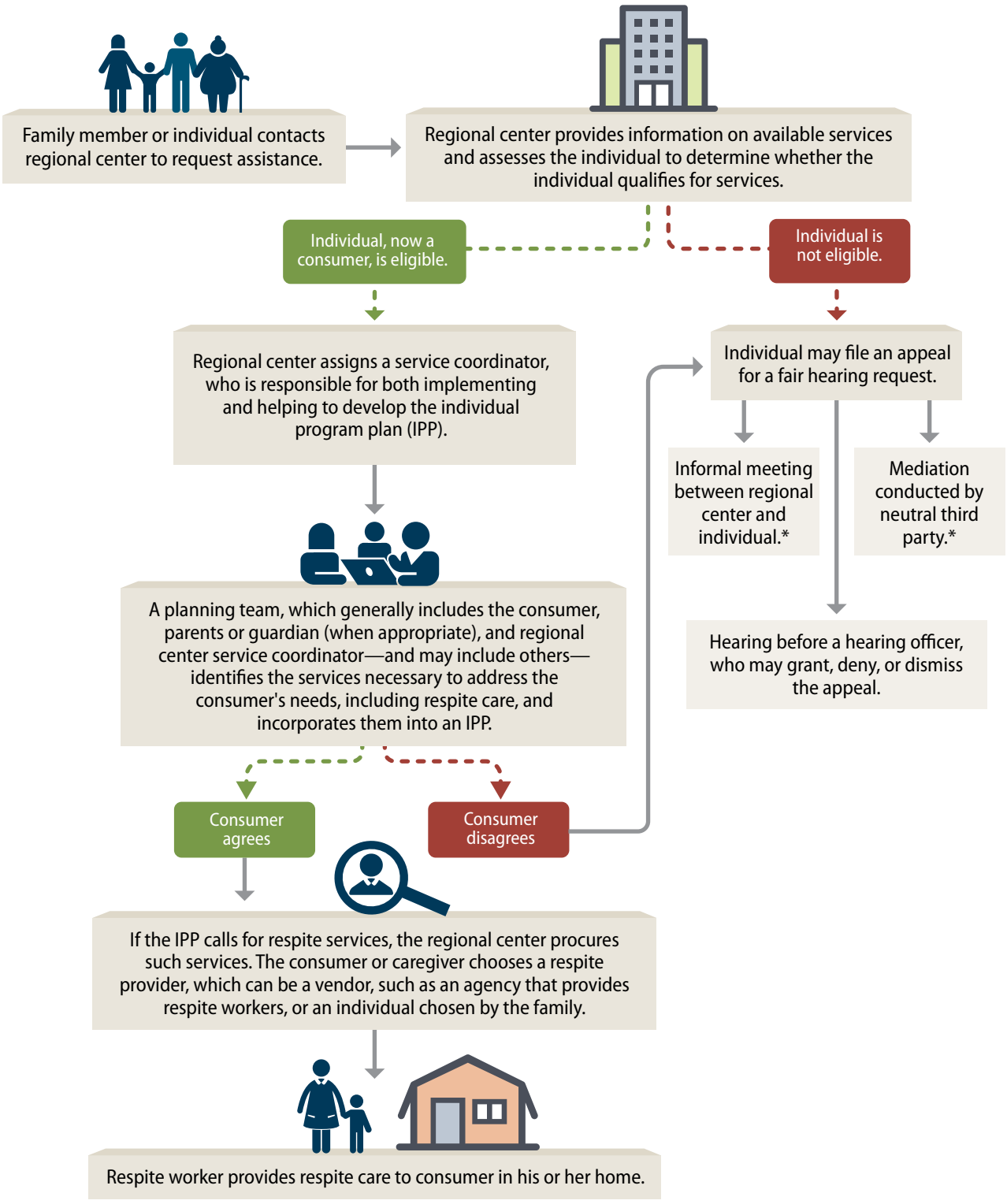
- Assess individuals and determine whether they are eligible for services.
- Develop, purchase, and coordinate services for eligible individuals and their families.
- Authorize and contract with vendors to provide services as needed.
- Reimburse vendors (such as respite agencies or FMS companies) for services provided to the consumer by the vendor or respite worker, based on a pre-established hourly rate.

Source: State law and DDS documentation.

Regional Centers

Each regional center serves a specific geographic region that includes one or more counties. We reviewed the policies and procedures at four regional centers: Golden Gate, which serves 10,000 consumers; Inland, which serves 41,000 consumers; San Andreas, which serves 18,000 consumers; and San Diego, which serves 35,000 consumers. The text box shows some regional center responsibilities, such as being responsible for determining individuals' eligibility. Figure 2 illustrates the process families must use to obtain in-home respite services.

Figure 2
Families Obtain In-Home Respite Services Through Regional Centers


Family member or individual contacts regional center to request assistance.
Regional center provides information on available services and assesses the individual to determine whether the individual qualifies for services.
Individual, now a consumer, is eligible.
Individual is not eligible.
Regional center assigns a service coordinator, who is responsible for both implementing and helping to develop the individual program plan (IPP).
Individual may file an appeal for a fair hearing request.
Informal meeting between regional center and individual.*
Mediation conducted by neutral third party.*
Hearing before a hearing officer, who may grant, deny, or dismiss the appeal.
A planning team, which generally includes the consumer, parents or guardian (when appropriate), and regional center service coordinator—and may include others—identifies the services necessary to address the consumer's needs, including respite care, and incorporates them into an IPP.
Consumer agrees
Consumer disagrees
If the IPP calls for respite services, the regional center procures such services. The consumer or caregiver chooses a respite provider, which can be a vendor, such as an agency that provides respite workers, or an individual chosen by the family.
Respite worker provides respite care to consumer in his or her home.

Source: State law and DDS documentation.

* These steps are optional.

In-Home Respite Service Delivery Options

DDS has historically offered respite services primarily through three delivery options, and it has recently begun offering a fourth option, as shown in Figure 3. Hourly rates that regional centers pay for respite services vary among the four regional centers we reviewed, with FMS rates being generally the lowest—ranging from about $22 to $26 per hour. Employer-of-Record (EOR) rates range from approximately $25 to $29 per hour, and In-Home Respite Service Agency (Agency) rates are the highest—ranging from about $33 to $38 per hour. The Agency and EOR rates include the pay for the respite worker and certain administrative expenses of the vendor, as applicable. The FMS rates are intended to cover pay and benefits for the respite worker. In addition, state regulations allow FMS vendors, which assist families and consumers with tasks such as processing payroll, to receive a payment of up to $95 per month per consumer to cover their administrative expenses.

Figure 3
Families Can Choose How They Receive In-Home Respite Services From Among Multiple Service Options

In-Home Respite Service Agency (Agency)

- The family chooses an approved vendor to provide a respite worker when needed.
- The vendor is responsible for hiring, scheduling, and supervising respite workers to serve families as needed.

Employer-of-Record (EOR)

- The family selects a respite worker, who is then hired by a respite vendor, which acts as the employer-of-record.
- The family may be responsible for training, scheduling, and supervising the respite worker, depending on the vendor. The respite vendor processes the worker's payroll and employment documents.

Financial Management Services (FMS)

- The family hires an in-home respite worker and becomes the employer or co-employer.
- The family is responsible for training, scheduling, and supervising the respite worker.
- An FMS vendor assists the family by processing the respite worker's payroll, employment documents, insurance, and taxes.

Self-Determination Program*

This option provides families with a single annual budget for all services. The families decide how to spend those funds on services, including respite services, and can hire their own support workers.

Source: State law, DDS documentation, and regional center documentation.

Note: The FMS option is also referred to as Participant-Directed Services.

* After piloting this delivery option to a small number of families in 2018, DDS added this option statewide in July 2021. Because it is relatively new and was not widely used during our audit period, we did not analyze it as part of our audit.

According to state law, it is the Legislature's intent that services provided by regional centers should be focused on the families and should take into account the preferences and choices of the consumer, among other things. As such, family caregivers have discretion to select any of the options they want to use to receive in-home respite care services.

The COVID-19 pandemic had some effect on families' overall use of in-home respite services since March 2020. Specifically, some families did not want to have an unfamiliar person in their home for fear of exposure to the coronavirus, which may have affected the options they used. For the five fiscal years we reviewed (2016–17 through 2020–21), we considered the impact the COVID-19 pandemic had on the use of in-home respite services, as necessary.

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DDS Has Not Taken Critical Steps to Address Disparities in the Use of In-Home Respite Services

Key Points

- Some families were unable to access respite services because of barriers such as a lack of available workers and difficulty finding workers who speak the same language as the family or who have specific training.
- Although DDS verifies that regional centers identify barriers to families' use of regional center services by obtaining feedback from stakeholders, it has not ensured that the regional centers take sufficient actions to reduce disparities in accessing in-home respite services.

Some Families Face Significant Barriers to Receiving Respite Services That Affect Their Ability to Care for Their Family Members

There are significant barriers that prevent some families from receiving critical in-home respite services. According to DDS data, on average, roughly 21 percent of caregivers authorized each year to receive in-home respite services do not use any of these services, which could be caused by such barriers. To identify barriers and other issues that caregivers face when using respite services, we surveyed more than 22,000 users of in-home respite services at the four regional centers we reviewed and received nearly 3,600 responses.[1] Our survey results showed that nearly one-third, or 950, of approximately 3,000 respondents who were authorized for hours experienced barriers or challenges to using in-home respite services. Collectively, our survey of users of in-home respite services, our review of feedback from stakeholders—including the families of consumers—compiled by the regional centers, and our review of 21 consumer appeals and related documents at each of the four regional centers revealed four significant barriers, as Figure 4 shows. The most common barrier that users reported in our survey was a lack of available respite workers for the times needed. In fact, of the nearly 950 survey respondents who reported experiencing barriers, nearly 70 percent, or 650, identified the lack of available respite workers for the times needed as a barrier or challenge to using in-home respite services.

These barriers can have significant impacts on families that rely on in-home respite services to care for their family members. As Case Example 1 shows, a lack of available workers prevented a family from

Case Example 1

One caregiver who responded to the survey reported being unable to find a respite worker.

The caregiver stated that its provider had no workers available in the area, leaving the caregiver unable to use the approved 90 respite hours per quarter.

Consequently, the caregiver has not received respite services for more than six months.

Source: Survey responses from in-home respite consumers at four regional centers.

[1] Some of the 3,600 respondents indicated that they were not authorized for respite services, and others did not answer every question on the survey.

receiving any in-home respite care, thereby depriving the family of the benefits of such care. Similarly, another family responded that they were unable to keep the consumer in their home as a result of not being able to access respite services. Other caregivers explained that the lack of respite services prevented them from being able to attend to other personal needs, such as their own medical appointments, therapy, or grocery shopping. State law describes that in-home respite services are designed to relieve family members from the constantly demanding responsibility of caring for the consumer and to assist them in keeping the consumer at home. Further, studies have shown that respite services can have positive impacts on family caregivers. One review, published by the *International Journal of Science and Research Methodology*, stated that respite care can improve the mental and physical health of family members and can reduce stress for the caregivers. Conversely, the review stated that a lack of respite care can cause caregivers to have a harder time taking care of consumers.

Figure 4
Families Report Barriers to Receiving In-Home Respite Services

LACK OF AVAILABLE WORKERS
In some areas, there is an insufficient supply of respite workers because of low reimbursement rates or scheduling difficulties.
INCOMPATIBILITY
Some families struggle to find respite workers with whom they are comfortable, personally or culturally.
LANGUAGE GAPS
Families have difficulty finding respite workers who speak their language.
SHORTAGE OF SPECIALIZED WORKERS
There is a shortage of respite workers trained to work with particular needs, including specific behaviors.

Source: Survey of families using in-home respite services, review of feedback from stakeholders that regional centers compiled, and analysis of consumer appeals at the four regional centers we reviewed.

Several factors contribute to these barriers, including low pay for respite workers and scheduling difficulties. Many caregivers identified low pay rates as a barrier, making it difficult for them to find willing respite workers. For example, multiple survey respondents explained that they had to pay additional amounts out of pocket to supplement the wages that vendors pay respite workers. One respondent reported

paying $14 per hour out of pocket on top of the respite worker's standard wage to make it appealing for respite workers to work with the consumer. These extra payments can create financial hardship for some caregivers. When we asked DDS whether this practice was allowed, the deputy director of DDS's administration division (deputy director of administration) stated that DDS does not have a policy that addresses whether families are allowed to supplement respite worker wages. Case Example 2 shows how the low pay rate made it difficult for one family to continue respite services. Further, some family caregivers reported difficulties working with the respite vendors to schedule respite services. For example, one caregiver reported that the respite vendor required the caregiver to commit to a three-hour minimum of respite services to schedule a respite worker, even though the caregiver needed only one to two hours of respite care at a time. Because these barriers can create difficulties for family caregivers trying to use respite services, DDS should take steps to reduce these barriers.

Case Example 2

In its appeal to the regional center, a family explained that it has been unable to keep a respite worker in place because of low pay.

The family noted that the workers all leave for higher wages and that the family cannot afford to pay supplemental wages to keep a respite worker in place.

The family had not had consistent respite care for about a year and a half.

According to this family, not receiving services resulted in the family's health declining, marriage deteriorating, and the family being unable to maintain the consumer's care in the home.

Source: Regional center appeals case files.

DDS Has Not Taken Adequate Actions to Reduce Barriers to Using Respite Services

State law requires DDS and regional centers to solicit feedback from stakeholders to identify barriers to receiving services, including respite services. Regional centers must report to DDS annually on the results of these stakeholder interactions and identify actions to reduce disparities and increase equity in families' use of respite services. Disparities, for example, can include families of one ethnicity using or being authorized for a higher amount of respite funding than families of another ethnicity. State law also requires DDS to consult with stakeholders to review demographic data and identify barriers to families' equitable access to respite services as well as actions to reduce disparities and increase equity. As the oversight agency responsible for ensuring that consumers have equal access to all services, state law requires DDS to allocate funding to the regional centers in order to implement the plans and recommendations developed as a result of stakeholder consultations. Thus, we would expect DDS to ensure that regional centers develop sufficient actions to address disparities and report to it on the implementation of those actions or recommendations. However, as Figure 5 shows, although DDS ensured that the regional centers we reviewed solicit feedback from stakeholders and report annually to it on disparities and challenges that families experience, it did not ensure that they identify specific, measurable actions and timelines for reducing these barriers.

Figure 5
DDS Has Not Taken Sufficient Steps to Minimize Barriers to Usage of Respite Services

DDS ENSURES THAT REGIONAL CENTERS ...

- ✓ Solicit feedback from stakeholders to identify barriers to use of in-home respite services.
- ✓ Report annually to DDS on the disparities and challenges families experience in accessing respite services, based on the results of stakeholder meetings, and identify corrective actions.

BUT IT DOES NOT ENSURE THAT REGIONAL CENTERS ...

- ✗ Indicate measurable action items and timelines for how they plan to reduce disparities and barriers.
- ✗ Specify outcomes to measure how well they have minimized disparities and barriers.
- ✗ Track progress annually on the actions they have taken to reduce disparities and barriers.

Source: State law, regional center annual reports, and interviews with DDS staff.

From fiscal years 2016–17 through 2019–20, the regional centers' planned actions to remove barriers and reduce disparities in the use of respite services have been insufficient. Although some of the actions the regional centers identified were described in detail, they often did not include measurable actions with expected outcomes or timelines, and many other actions were presented only at a high level, with insufficient detail. For example, one regional center's action broadly stated that "we continue to staff a disparity specialist position to provide culturally specific training to regional center and vendor staff" but did not identify expected outcomes or timelines. DDS neither ensures that the regional centers develop sufficient actions to reduce disparities and increase equity, nor does it follow up on these actions that are developed by requiring regional centers to report on the status of these actions or recommendations.

Furthermore, we reviewed DDS's efforts to reduce disparities in consumers' use of respite services across all regional centers and found that even though DDS has taken actions that could reduce disparities, such as issuing grants and holding meetings with stakeholders, it has

not analyzed these efforts to determine their impact. The deputy director of administration explained that DDS expanded some grant projects statewide after determining that they were successful in increasing access to services. Although the deputy director provided two examples of such efforts, neither example included documentation of a comprehensive analysis, such as a review of service usage by demographic category, to demonstrate reduced disparities. In fact, because state law required it to do so, DDS recently hired a contractor to, in part, determine the efficacy of its efforts to reduce disparities and develop metrics for assessing the impact of future efforts. The contract requires the contractor to complete its analysis and submit a report by December 31, 2022. Nonetheless, DDS's actions thus far have not been sufficient to reduce disparities or ensure that all families are able to access the respite services they need.

The deputy director of administration acknowledged that DDS is aware of possible barriers to families accessing respite services but indicated that it has recently taken some actions to achieve greater access. One of those barriers is the lack of availability of respite workers. As required by state law, DDS's consultant completed a rate study in 2019 that recommended increasing the payment rates for respite services. Subsequently, the State enacted legislation in 2021 requiring that DDS implement the new rates incrementally between April 2022 and July 2025. In June 2022, the State accelerated that timeline and required DDS to fully implement the new rates by July 2024. For example, the table shows current and future payment rates for one regional center, Golden Gate, based on the rate study and implementation schedule.

Table
In-Home Respite Pay Rates Will Increase Over the Next Two Years

GOLDEN GATE REGIONAL CENTER	MARCH 2022 RATES IN EFFECT BEFORE RATE STUDY INCREASES	APRIL 2022 CURRENT RATES AFTER FIRST RATE STUDY INCREASE	JANUARY 2023 RATE AFTER SECOND RATE STUDY INCREASE	JULY 2024 FULL RATE STUDY RATES
Agency	$26.73	$29.37	$32.02	$37.30
EOR	21.98	23.79	25.60	29.21
FMS	19.18	20.91	22.64	26.09

Source: DDS rate study, DDS rate information, regional center rate information, and calculations based on state law.

Note: State law increased the rates in increments based on the difference between the full rate study rates and the rates in effect on March 31, 2022. These increases are 25 percent of the difference at April 1, 2022, 50 percent of the difference at January 1, 2023, and the full rate study rates at July 1, 2024. Because the current and future rates vary by regional center, we present the rates for Golden Gate as an example of how the rates are expected to change over time.

The deputy director of administration believes that these rate increases will help increase the availability of respite workers. However, the increases may not be sufficient because the rate study's assumptions rely on a long-term average that is lower than the current one-year inflation rate as of March 2022. Specifically, DDS used a 10-year average annual inflation rate of 4.9 percent for 2010 through 2020 when it updated the 2019 rates in February 2022, whereas California's one-year inflation rate—as of March 2022—is 8.5 percent. California's current one-year rate of inflation may mean that the rates updated by using the 10-year average inflation rate will be less desirable for incentivizing individuals to work as respite workers. DDS indicated it does not plan to perform another rate study, and state law does not require it to regularly do so. DDS stated on its website in response to a question about annual cost-of-living adjustments that updates to the rate models after 2025 would be subject to approval through the State's budget process. Consequently, the planned rate increases may not be enough to attract and retain a sufficient number of respite workers, which emphasizes the need for DDS to regularly assess and update rates.

Further, DDS has been slow to implement other recommendations from the payment rate study that could reduce barriers. As the text box shows, the 2019 rate study also included recommendations that DDS adopt higher rates for workers who speak languages other than English and for workers with specialized training. However, in July 2021, the Legislature declared that DDS had not implemented these recommendations from the rate study. DDS indicated that it is in the process of implementing a financial incentive for bilingual respite workers, which it anticipates will start during fiscal year 2022–23. Similarly, DDS is establishing a broad training program to provide training for skills including crisis prevention and to increase wages for those respite workers who complete the training. However, this program is still in the planning stages, and DDS does not anticipate its implementation until summer 2023. DDS also received funds in the fiscal year 2022–23 budget to provide stipends of up to $1,000 for respite workers who complete some training. Although these recommendations were included in the rate study, the rate model implemented in April 2022 does not include enhanced rates for bilingual respite workers or those who have specialized training.

Key Payment Rate Study Recommendations

- Establish higher rates for respite workers who speak languages other than English.
- Establish higher rates for workers with specialized training.
- Implement rate models that can be regularly updated.
- Implement differentials to account for regional variance in costs.

Source: Rate study and state law.

Implementing these actions is particularly important because DDS data reveal some disparities in consumers' use of in-home respite services. As required by state law, DDS collects data on in-home respite usage, including by demographic and diagnostic category, from the regional centers. We reviewed data that DDS maintains

from all 21 regional centers to identify disparities in respite usage by the categories in the text box.[2] In our review, we found that adult consumers tended to use more of the authorized funding for in-home respite services than younger consumers.[3] Specifically, the median consumer over the age of 21 used more than 88 percent of their authorized funding for services over the five-year period we reviewed whereas the median consumer between age 3 and 5 used about 48 percent. Among disability diagnoses, we noted that the median consumer identified solely with an autism diagnosis used less of their authorized funding for respite services than consumers with most other diagnoses.

Categories Related to Respite Usage We Reviewed

- Age
- Disability diagnosis
- Ethnicity
- In-home respite service delivery option
- Language
- Residence

Source: Analysis of DDS data.

Further, we reviewed in-home respite usage of the 21 regional centers and found significant variations among the centers. For example, in fiscal year 2020–21, families at San Diego used a median of 27 percent of authorized funding for respite services while families at Golden Gate used a median of 90 percent. Moreover, we found that families that used the FMS option were more likely to use their authorized services than families that used the Agency or EOR options, which we discuss later in the report. Although these trends suggest there could be some barriers to the usage of in-home respite services, DDS has not analyzed the data in a way that would allow it to identify similar types of disparities, such as comparing the usage of and authorization for in-home respite services across the demographic categories. The deputy director of administration indicated that the analysis it currently performs is consistent with statutory requirements. However, by not performing an analysis similar to one described above, DDS is limiting its ability to identify these and other disparities.

Finally, although DDS's data contain information specific to the FMS option, they do not contain information to differentiate between the Agency and EOR options. As a result, DDS can only compare FMS to combined data for the EOR and Agency options. Similarly, because DDS's data do not consistently contain the number of in-home respite hours authorized and hours used for each family, DDS is unable to identify disparities between hours authorized and the hours used on average for certain demographic categories.

Please refer to the section beginning on page 3 to find the recommendations that we have made as a result of these audit findings.

[2] We include information about most of these categories in our interactive dashboard at http://www.auditor.ca.gov/reports/2021-120/supplementalgraphics.html.

[3] DDS does not consistently track the number of respite hours awarded by regional centers, but it does maintain data on the dollar amounts regional centers spend on authorized respite services. We reviewed the usage of authorized funding to identify disparities.

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Because of DDS's Insufficient Oversight, Some Regional Centers May Impose Inappropriate Limits on Respite Services

Key Points

- Since the 2018 repeal of the law applying limits on the purchase of in-home respite services, DDS has not adequately ensured that regional centers are no longer applying inappropriate limits on the number of in-home respite hours a consumer may receive.
- In the absence of clear processes or documentation by the regional centers, DDS cannot determine that regional centers allocate in-home respite hours to consumers appropriately.

DDS Needs to Ensure That Regional Centers' Policies Are Not Inappropriately Limiting Families' In-Home Respite Hours

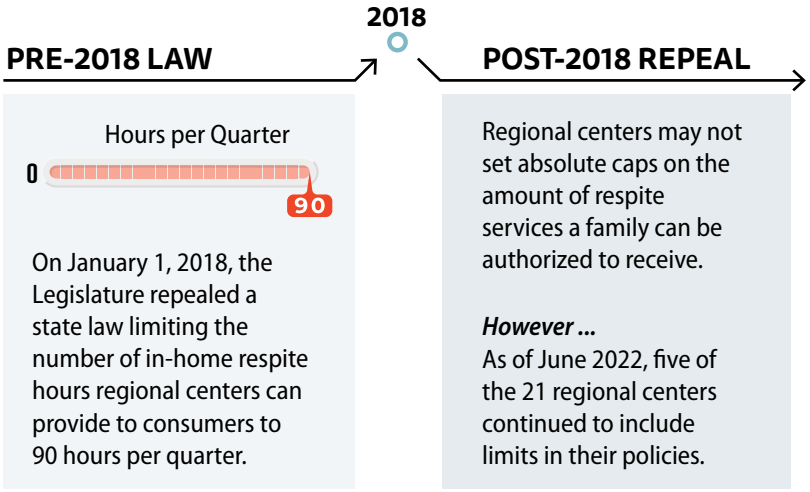
Although a state law limiting the number of in-home respite service hours was repealed in 2018, five of the State's 21 regional centers' respite policies (24 percent) still contain provisions limiting the quantity of respite services authorized. State law declares the Legislature's intent that each consumer's planned services, including respite services, be centered on the individual needs of the consumer and family. It also requires regional centers to consider services and support to be flexible and individually tailored to the consumer and family. However, to control costs, state law prior to 2018 limited regional centers to authorizing no more than 90 hours per quarter of in-home respite services for each family. As of January 1, 2018, state law repealed that restriction. This change benefits families that may have been otherwise eligible for more than 90 hours of respite per quarter but could not obtain them because they were subject to the limit. In August 2017, DDS informed all regional centers of this upcoming change in state law and requested that they conduct outreach to consumers and their families—including to those who may not typically avail themselves of respite services but who may benefit from them—to inform these potential users of the repeal of the limit. DDS also directed all regional centers to revise their policies pursuant to the upcoming change in law.

As part of DDS's responsibility to monitor regional centers, state law requires it to review and approve regional center policies and guidelines prior to their implementation. When we asked DDS what actions it has taken since August 2017 to ensure that regional centers no longer impose the 90-hour limit, the manager of the northern office in the Office of Community Operations (northern operations manager) stated that if any regional center were to place a limit, DDS would have known because the policy would not have been approved when the regional center sent in the policy for DDS to review.

Nonetheless, in our review of all 21 regional centers' policies, we found five that continue to have policies that impose a limit on respite hours, as shown in Figure 6. One of the regional centers with policies limiting respite hours is Golden Gate. According to the northern operations manager, whose office oversees that regional center, DDS approved this policy because it included a process for the regional center to allow exceptions to its authorization determinations. For example, if a regional center authorized a certain number of respite hours that a consumer or

family caregiver did not believe was sufficient, they could ask the regional center to make an exception and authorize additional hours. However, we disagree that an exceptions process is sufficient to comply with the Legislature's intent in repealing the hourly cap. Because the repeal in state law removed hourly caps on the authorization of respite services, regional center policies that reference limits on respite hours are inconsistent with the intent of the Legislature and risk creating the impression among consumers, families, and regional center staff that an hourly cap is still in place. Moreover, such policies also create additional barriers to families' accessing respite services by imposing an hour limit and requiring a family to seek an exception.

Figure 6
Five Regional Centers' Policies Stipulate a Limit on In-Home Respite Services


2018
PRE-2018 LAW
POST-2018 REPEAL
Hours per Quarter
0
90
On January 1, 2018, the Legislature repealed a state law limiting the number of in-home respite hours regional centers can provide to consumers to 90 hours per quarter.
Regional centers may not set absolute caps on the amount of respite services a family can be authorized to receive.
However ...
As of June 2022, five of the 21 regional centers continued to include limits in their policies.

Source: State law and regional center policies.

Note: The five regional centers with limits in their policies are Far Northern, Frank D. Lanterman, Golden Gate, Orange County, and San Gabriel/Pomona.

We were unable to determine whether regional centers actually impose limits on respite hours in practice. Our testing of authorization files identified many instances when regional centers did not document their rationale for the number of respite hours they awarded. Neither state law nor DDS requires regional centers to document such rationale. However, prudent business practices suggest that regional centers need to consistently demonstrate how they determined the appropriate number of respite hours to authorize so that DDS, family caregivers, and consumers have assurance that regional centers are not applying limits on respite hours.

Staff at DDS and the regional centers indicated that respite hours are authorized on a case-by-case basis depending on each family's circumstances. State law requires regional centers to consider services and other support in the community, home, work, and recreational settings

when determining how many respite hours to authorize. However, neither this broad mandate nor state regulations specify how regional centers must carry out and document these considerations. In fact, the regional centers we reviewed do not follow a consistent process for documenting how they determine the number of respite hours they authorize. One of the four regional centers we reviewed—San Diego—has a respite assessment tool that it requires its staff to use to determine the number of respite hours to award. The assessment tool considers several factors, as the text box shows.

Factors San Diego Considers in Its Respite Assessment Tool

- **Age:** The age of the consumer.
- **Medical Needs:** The extent to which the consumer has medical conditions that require medical care.
- **Daily Living Activities:** The extent to which the consumer requires reminders, prompting, or physical assistance with completing activities, such as going to the bathroom, dressing, or eating.
- **Mobility:** The extent of the consumer's mobility.
- **Emotional and Behavioral Needs:** The extent to which the consumer displays challenging behaviors.
- **Safety and Supervision Needs:** The extent to which the consumer attempts to run or wander away and requires supervision to prevent injury or harm.
- **Family Situation:** The consumer's family situation, including whether it is a one- or two-parent family, whether the primary caregiver's health affects the ability to care for the consumer, and whether the family has other consumers living in the home.
- **Day Program Attendance:** The extent to which the consumer attends school or a day program.

Source: San Diego respite assessment tool.

San Diego assigns a score for each of these factors and uses the total score to determine the number of respite hours to authorize. Using such a tool seems reasonable because it can help ensure a consistent approach to determining the number of respite hours to authorize. Two other centers—Golden Gate and San Andreas—each have a similar respite assessment tool that they indicate that they recommend, but do not require, their staff use. The fourth center—Inland—does not use an assessment tool and instead takes a less formal approach to documenting its rationale for awarding respite hours.

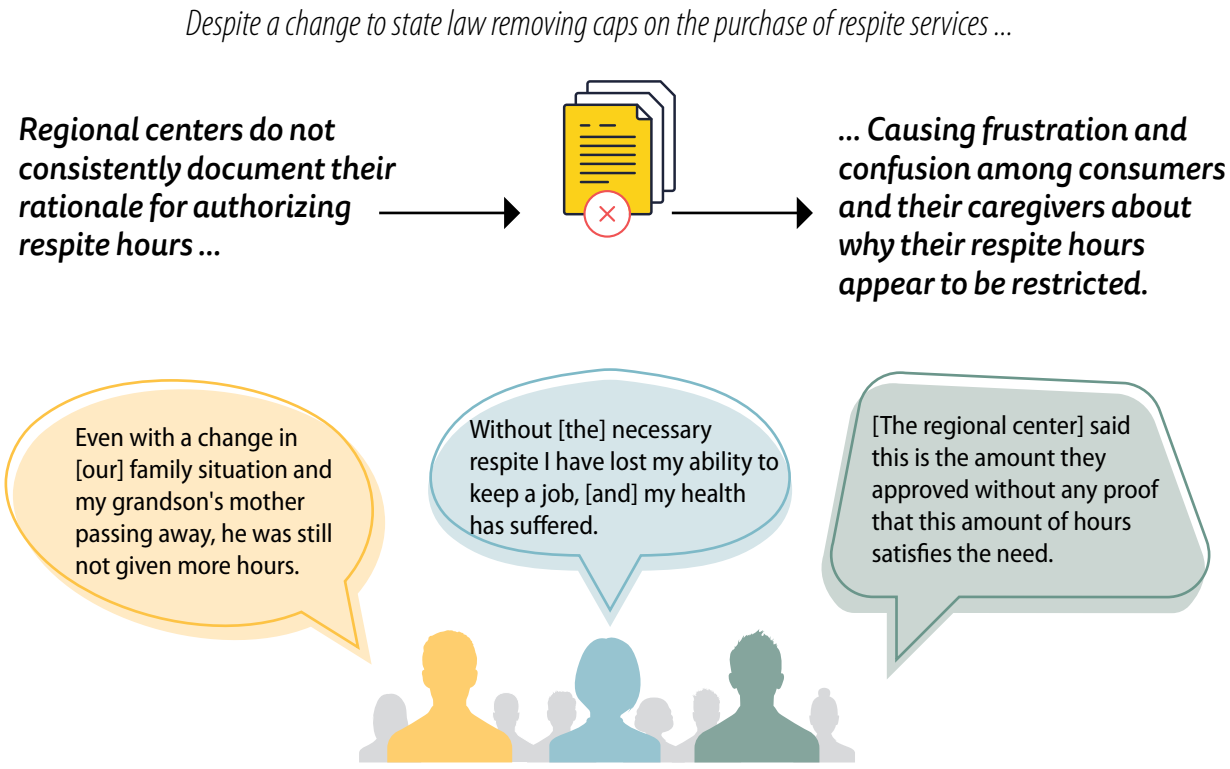
In its role overseeing regional centers, DDS is in an ideal position to develop a standard method for regional centers to justify their determination of hours and to document their rationale. Doing so would ensure transparency and support the regional center's decisions when responding to complaints or appeals about respite hours they authorize. According to its deputy director of the community services division, DDS believes that the Individual Program Plan process—the planning process during which the regional center assesses the needs of the consumer—should be the driver for decisions on the appropriate amount of services for each individual. We do not disagree, but we maintain that regional centers should record their reasoning for the number of hours they award each consumer, and DDS is best suited to ensure that they do so.

Without Clear Processes or Documentation, DDS Cannot Ensure That Regional Centers Are Appropriately Authorizing In-Home Respite Hours for Families

DDS's inadequate oversight of regional centers means it is unable to determine whether regional centers are inappropriately limiting respite hours. Many consumers we surveyed raised concerns about the sufficiency of the respite hours that regional centers authorized for them. Although our testing of authorization files at four regional

centers did not determine that any were clearly imposing limits on respite authorizations, appeals cases showed that many families believed their respite hours were insufficient. Because we found that regional centers often did not document their rationale for the number of respite hours they award, the centers were unable to justify the appropriateness of the hours they authorized. For example, our review of five consumer files at each of the four regional centers found that the centers were unable to consistently provide a rationale for how they determined the amount of respite hours they authorized. The regional centers provided no rationale in 9 of the 20 files we reviewed. The remaining 11 files included some level of rationale, either in narrative form or a respite assessment tool. Figure 7 shows the frustration and confusion that can arise because regional centers' rationales for awarding respite hours are not adequately documented.

Figure 7
Many Caregivers Expressed Concerns That Regional Centers Impose Unreasonable Limits on Authorized Respite Hours


Despite a change to state law removing caps on the purchase of respite services ...
Regional centers do not consistently document their rationale for authorizing respite hours ...
... Causing frustration and confusion among consumers and their caregivers about why their respite hours appear to be restricted.
Even with a change in [our] family situation and my grandson's mother passing away, he was still not given more hours.
Without [the] necessary respite I have lost my ability to keep a job, [and] my health has suffered.
[The regional center] said this is the amount they approved without any proof that this amount of hours satisfies the need.

Source: State law, our review of regional center respite authorizations, and survey responses from families using in-home respite services at four regional centers.

Although state law no longer imposes a hard cap on the number of respite hours that regional centers can authorize for each family, eligibility for respite services does not provide for an unlimited

number of hours. State law requires regional centers to determine the appropriate number of hours for each family depending on the individual circumstances of the consumer and his or her family. For example, the DDS Office of Community Relations assistant deputy director (assistant deputy director) explained that a situation in which two families have similarly aged children with developmental disabilities may result in different numbers of respite hours authorized for the two families. The assistant deputy director stated that a variety of factors contribute to a regional center's assessment of respite hours to authorize. For instance, one family's child could attend school regularly—rendering the family responsible for fewer hours of care—while the other family's child may be at home full time, thus requiring more in-home care.

Because regional centers do not have a consistent process for determining the number of respite hours to authorize and for documenting those decisions, it is difficult for DDS to determine the rationale that regional centers use to award respite hours for some families. The examples we saw in appeals and survey responses illustrate that many consumers are concerned about how much in-home respite care is authorized. For instance, our review of appeals from fiscal years 2017–18 through 2021–22 at the four regional centers found that in 91 of 135 cases (67 percent), consumers filed fair hearing appeals to increase their number of authorized respite hours. Our review also identified some families that had to go through the formal appeal process in order to access what they considered to be an adequate number of respite hours. Case Example 3 describes one family's experience, as stated in its appeal.

Case Example 3

A consumer requested an increase in respite hours from 90 hours per quarter to 180 hours per quarter.

The regional center denied the request, stating that the services and support currently in place were sufficient to maintain the consumer in the family home and provide the family with a periodic break from care. However, the regional center was willing to temporarily increase the number of respite hours for three months.

The consumer appealed the decision, and the regional center stood by its decision that 90 hours per quarter of respite care was sufficient.

The parties subsequently reached an agreement whereby the regional center authorized an increase of respite from 90 to 144 hours per quarter.

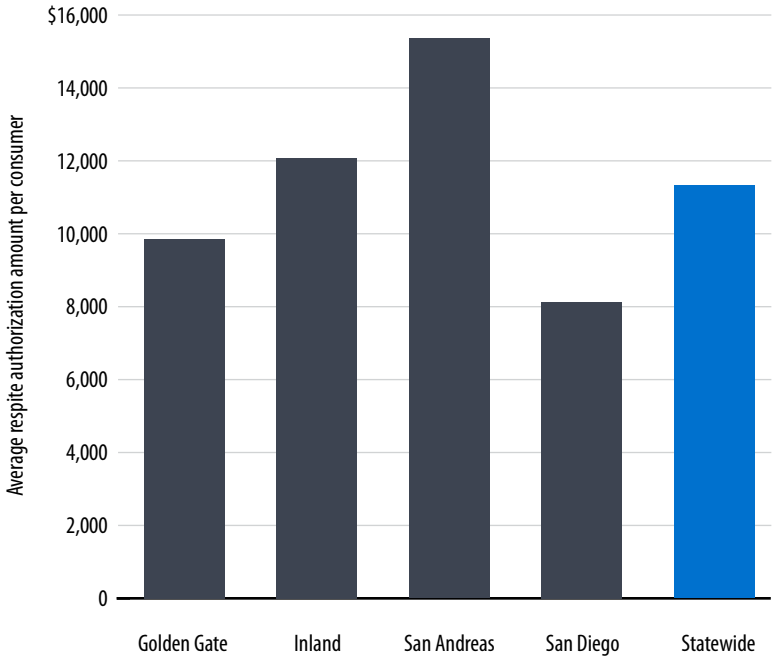
The process took more than three months from the initial request to the resolution of the appeal.

Source: Regional center appeals case files.

Similarly, nearly 2,150 respondents to our survey—more than two-thirds who were authorized for hours—said they were subjected to limits on their respite hours. Further, more than 450 of these respondents described negative impacts of limited respite hours.

Although the deputy director of administration indicated that DDS does not track the number of respite hours awarded by regional centers, he did not consider this to be a data limitation because DDS does collect data on the dollar amounts authorized for respite by regional centers. When we reviewed these data, we found variations in the amounts of respite authorizations across regional centers, suggesting that the regional centers use different approaches for determining the number of respite hours to award. As shown in Figure 8, the average respite authorization per consumer for fiscal year 2020–21 varied among the four regional centers we reviewed from roughly $8,000 per consumer at San Diego to more than $15,000 per consumer at San Andreas.

Figure 8
Average Annual In-Home Respite Authorization Amounts Per Consumer Vary Widely Across Regions, Fiscal Year 2020–21



Source: DDS in-home respite authorization data.

Note: Total amounts authorized for in-home respite services have been adjusted according to DDS's rate adjustment factor to account for differences in respite pay rates among regional centers. The unadjusted amounts still show variation, ranging from $8,100 to $13,400, while the adjusted amounts shown in the figure range from $8,100 to $15,400.

In response to our concern, the deputy director of administration acknowledged that it would be beneficial for regional centers to use a consistent process when awarding respite hours. Such a process would help ensure that regional centers provide transparency and authorize respite hours equitably. Until DDS takes action to require regional centers to develop formal processes and document the rationale for their decisions, DDS, families, and consumers will be unable to determine with certainty whether regional centers are complying with the law by not imposing inappropriate limits on respite hours and by ensuring that consumers and families are awarded sufficient respite hours to meet their needs.

Please refer to the section beginning on page 3 to find the recommendations that we have made as a result of these audit findings.

Not All Families Have Sufficient Access to a Potentially Beneficial Respite Service Option

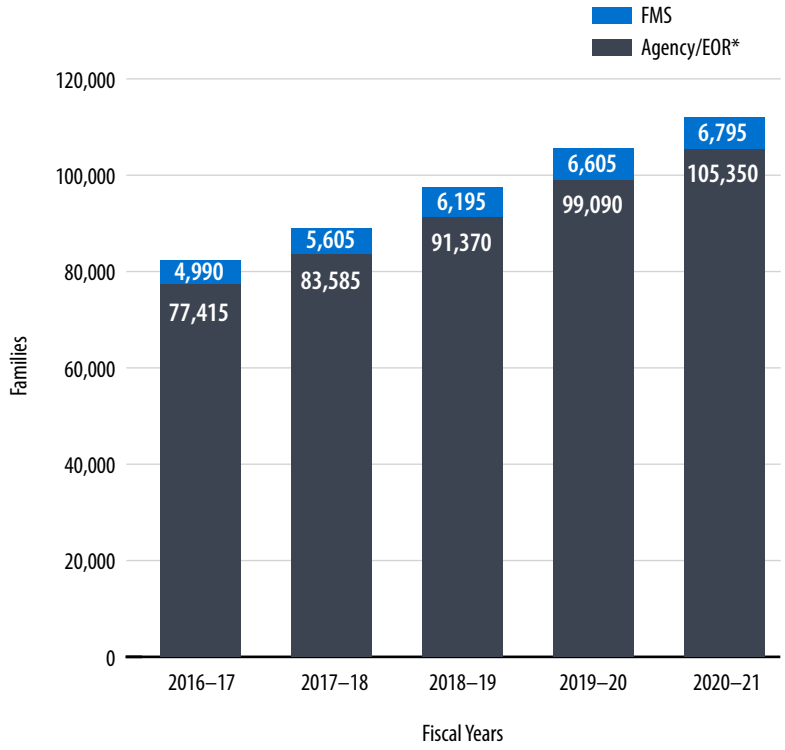
Key Points

- Many families do not use the FMS option for in-home respite services, precluding them from gaining the benefits it provides.
- Even though the FMS option is the preferred choice for some families, DDS has not ensured that all regional centers actually offer it to families.

Although the FMS Option Can Reduce Some Barriers to Families Receiving Respite Services, It Is the Least-Used Delivery Option

Of the three in-home respite service delivery options that we reviewed, FMS (also known as Participant-Directed Services) has the lowest utilization. Figure 9 shows that significantly fewer families have used the FMS option during the past several years than the Agency and EOR options combined. This low utilization is concerning because FMS could be the most beneficial option for many families needing these crucial in-home respite services.

Figure 9
Significantly Fewer Families Use the FMS Option Than the Agency and EOR Options



Source: DDS data.

* DDS tracks the number of families that use the Agency option and the EOR option in aggregate but does not identify totals for each option.

Why Some Caregivers Chose the FMS Option

- "Because I need someone that me and my son are comfortable with."
- "It's flexible and more convenient to schedule. Also, my daughter is familiar [with the worker], and they are trusted."
- "I wanted the same respite worker all the time—my child would not handle a new person all the time. I also wanted the ability to schedule when I needed them myself. I did not want the possibility of having to call the respite company and request help for a date and no one be available."
- "[The] Agency [option] did not have enough available workers."
- "I want a trusted worker and the flexibility of the scheduling."

Source: Survey responses.

Why Some Caregivers Chose the Agency Option

- "I liked that they [the workers] were vetted, background-checked, and approved."
- "I wasn't given another option."
- "The [vendor] has historically given us qualified workers."
- "It is difficult for me to recruit, train, and retain respite workers by myself."

Source: Survey responses.

Why Some Caregivers Chose the EOR Option

- "My daughter has behavioral issues and can be aggressive to strangers. She works best with family members and they also know how to care for her properly."
- "I know my child will be safe with someone I know and trust."
- "I could never get a respite caregiver for more than 4 years before finding my own."
- "This option allowed us to use a person we already know and trust. However, we were never able to get this person hired by a [vendor]. The process proved too difficult and unorganized."
- "I had better luck finding my own worker. It would have taken months for the [vendor] to find me a worker."

Source: Survey responses.

The three in-home respite options vary in how much the family is responsible for selecting, training, and scheduling a respite worker. Families we surveyed identified various reasons for choosing each of the three options, as the text boxes show. Increased usage of the FMS option could help reduce some of the barriers we discuss earlier. As Figure 10 shows, the FMS option has a unique structure compared to the other two options, which could make it the most beneficial option for some families. The flexibility of FMS enables families to choose a respite worker with whom they are familiar, which could address two of the key barriers family caregivers reported encountering—lack of respite workers who speak the same language as the family and lack of respite workers with whom the family is comfortable.

According to state law, it is the Legislature's intent that services provided by regional centers be focused on the families and take into account the preferences and choices of the consumers and their families, among other things. Because FMS can alleviate the barriers some families reported experiencing, the State could potentially benefit from its increased usage.

Figure 10
Each of the Three Respite Delivery Models Has Different Benefits and Drawbacks

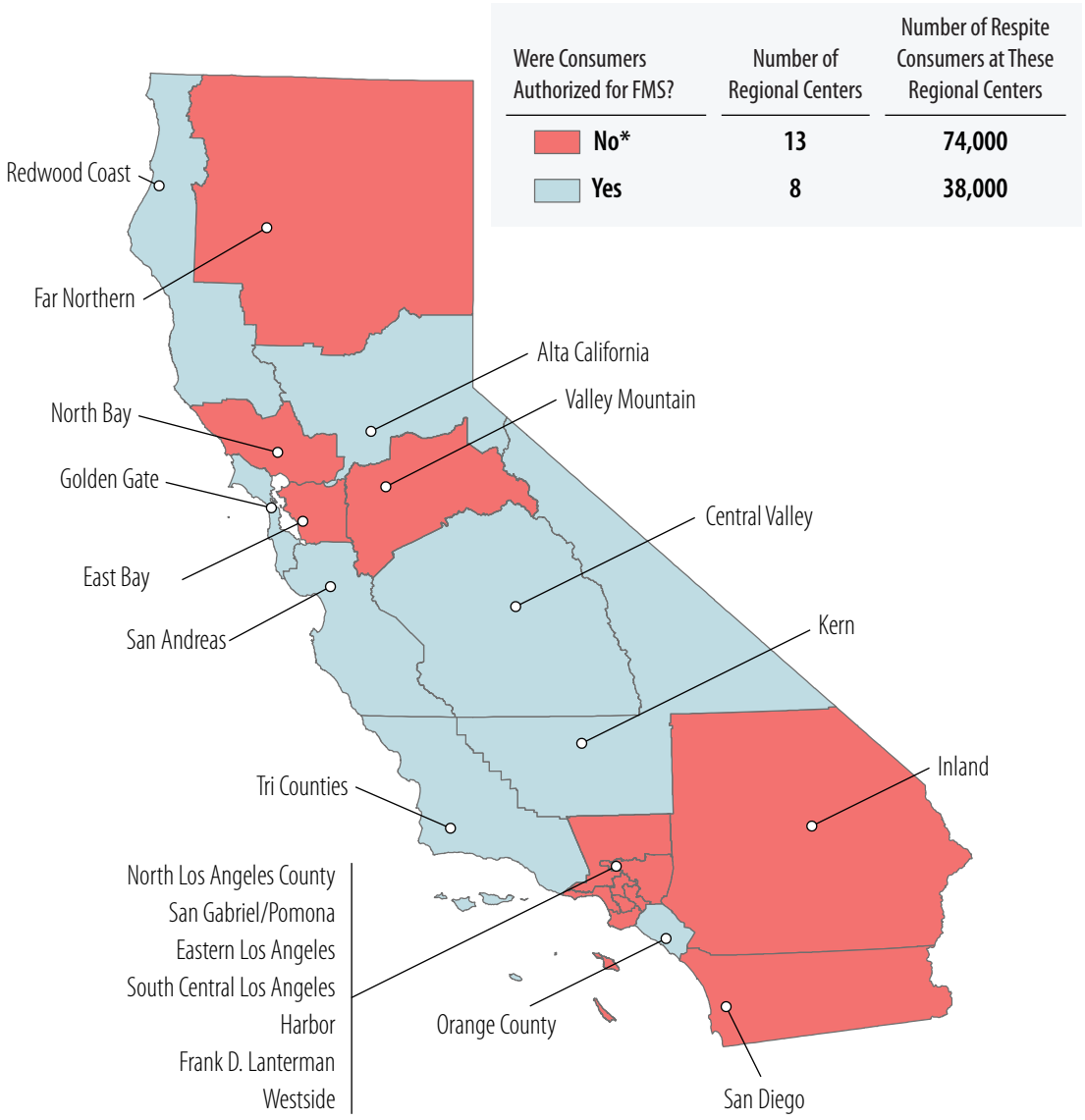
	In-Home Respite Service Agency (Agency)	Employer-of-Record (EOR)	Financial Management Services (FMS)
Choice of Respite Worker	Vendor provides the respite worker.	Family selects a respite worker and a vendor hires that worker.	Family selects and hires the respite worker either fully or as a co-employer.
Training, Scheduling, and Supervision	Respite vendor trains, schedules, and supervises the respite worker.	Either the family or vendor can be responsible for training, scheduling, and supervising the respite worker, depending on the vendor.	Family is responsible for training, scheduling, and supervising the respite worker.
Administrative Burden	Because the vendor is responsible for providing the respite worker, the family does not need to complete additional administrative steps related to hiring the respite worker.	Vendor places varying levels of qualification burden on the respite worker in the hiring process, which can include employment applications, interviews, and background checks.	Family has to complete additional paperwork related to hiring the respite worker at the beginning of the process, but the respite worker does not have as much qualification burden as under EOR.
Families That Could Benefit from the Option	Families that prefer a lower administrative burden or do not have a friend/family member to serve as the respite worker.	Families that want to choose the respite worker and not have the potential additional responsibilities related to training or directly hiring the respite worker.	Families that would like to have the most control over hiring and supervising the respite worker.

Source: State law and regional center contracts, policies, and procedures.

Neither DDS Nor Many Regional Centers Take Adequate Action to Ensure That the FMS Option Is Available to Families

Despite clear legislative intent that the provision of services should reflect the choices of consumers and their families, two of the four regional centers we reviewed rarely offer the FMS model and do little to inform consumers that it is an option they can choose. Consequently, the FMS option is not always made available to families that would otherwise benefit from using this option, particularly those that prefer more flexibility and want a respite worker whom they know and who speaks the same language. Based on our review of in-home respite usage data for fiscal year 2020–21, less than 1 percent of families use FMS at 13 of the 21 regional centers, as Figure 11 shows. FMS usage is low in some areas of the State, in part because DDS and some regional centers do not take adequate action to inform families about the FMS option and also because some centers do not offer the option.

Figure 11
The Majority of Respite Consumers in the State Are Served by Regional Centers That Seldom or Never Offer the FMS Option



Source: DDS authorization data for fiscal year 2020–21.

* These regional centers had less than 1 percent of their respite consumers authorized for the FMS option.

Two regional centers we reviewed—Golden Gate and San Andreas—were among the eight regional centers statewide that offered the FMS model—which we define as having more than 1 percent usage—and at both centers, a significant portion of their family caregivers elect to use the FMS option. Specifically, in fiscal year 2020–21, over half of Golden Gate's more than 2,500 family caregivers and 20 percent of San Andreas's nearly 6,800 family caregivers used the FMS option.

In contrast, during this same period, the other two regional centers we reviewed—San Diego and Inland—had very few or no family caregivers using the FMS option. Only 11, or less than 1 percent, of the more than 11,000 families using in-home respite services offered by San Diego used the FMS option in fiscal year 2020–21. Inland, despite having more than 15,000 families using in-home respite services, had no families using the FMS option in fiscal year 2020–21.

Our review of DDS data revealed that families are much more likely to make use of their authorized services under the FMS option than under the other options. Specifically, in fiscal year 2020–21, statewide median figures show that families choosing the Agency or EOR options used only 65 percent of their authorized services. By contrast, families that chose the FMS option used nearly 86 percent of their authorized services. These statistics show that when regional centers authorize FMS services for families, caregivers are likely to actually use more of the services.

DDS and some regional centers have reported limited availability of respite workers who speak languages other than English at Agency vendors. Our review of DDS data revealed that at the eight regional centers that offer the FMS option, non-English speakers were more likely to use the FMS option than the Agency or EOR options, relative to English speakers. We found a similar trend among Hispanic families, which use FMS services at a higher rate than non-Hispanic families. These results highlight the importance of ensuring that the FMS option is available to families at all regional centers.

San Diego explained that it does not have a vendor that provides FMS services, which may account for its low level of family caregivers using that option. Inland stated that it also does not have any vendors for FMS services because it has never chosen to offer that option, although it indicated that it would be willing to inquire with vendors about offering FMS services. In contrast, San Andreas uses a large company for FMS services that works with other regional centers throughout the State, and Golden Gate uses a national vendor to provide FMS services. Thus, regional centers that do not offer the FMS option could pursue the possibility of contracting with these types of vendors to provide needed FMS services. When we asked DDS what it does to ensure that regional centers offer FMS, the deputy director of administration indicated that it provides training

to regional centers and presentations to families on the FMS option. However, by not ensuring that regional centers actually offer FMS services, DDS is not guaranteeing that families have access to the option that may better suit their needs.

In addition, we found that Inland and San Diego conducted very little outreach to inform families of the FMS option. Both Inland and San Diego explained that they inform families about their options mainly during annual planning meetings with each family. However, these regional centers indicated that they do not present FMS as an option to families during those meetings and instead primarily offer the EOR and Agency options. As Case Example 4 shows, Inland did not offer FMS to a family in part because it believed that the family's needs could be met through the EOR or Agency option. Inland prevented this family from accessing the FMS option, so it had to use another option for respite services. However, FMS has unique benefits for some families that are not available through EOR. For example, under the FMS option, families have more control because the family caregiver—instead of the vendor—is responsible for training, scheduling, and supervising the respite worker, whereas a vendor sometimes performs those duties under the EOR option. Because these regional centers seldom inform families of the FMS option, the families may not be aware of it and its potential benefits.

Case Example 4

A family at Inland requested to use the FMS option for respite services.

Inland denied the family's request for FMS respite and instead offered to provide the EOR option to the family. Inland insisted that FMS was not appropriate or needed because the family's respite needs could be met through the EOR or Agency option.

Inland explained that it promotes the EOR option because it avoids the extra responsibility placed on families using the FMS option.

The family ultimately withdrew its appeal and pursued another option for respite services.

Source: Regional center appeals case files.

Some families indicated that trying to get their respite worker hired under the EOR option is burdensome. In our review of contracts for EOR and FMS vendors, we found that the EOR option presents more hiring requirements for respite workers than the FMS option. For example, one EOR vendor required that the prospective respite worker pass stringent hiring criteria, including an initial telephone interview, a comprehensive in-person interview, a skills demonstration test, and a clean background check.

In response to our survey, many caregivers reported that they were not aware of the FMS option. In fact, of the nearly 2,100 survey respondents who indicated that they used either the Agency or EOR option, only half were aware of the existence of the FMS option. In total, only around 450 survey respondents used the FMS option. The majority of these families stated that they prefer the FMS option because of the flexibility it provides. In addition, the websites for many regional centers provide minimal information about the three delivery options and only state that in-home respite services are available. Moreover, the outreach materials from the four regional centers we reviewed provided little information to describe the different respite

service options available or to articulate the benefits of each option so that families can make informed decisions. When the regional center staff members do not discuss each of the available options during their annual meetings with families, the lack of outreach information in other forms further inhibits a family's ability to become aware of and understand the available options.

Although the deputy director of administration acknowledged the low utilization of FMS and indicated that DDS could do more to inform families and increase awareness of this option, he stated that caregivers still have the EOR option, which is largely similar to FMS in that it allows families to choose respite workers. Inland and San Diego provided similar explanations for their lack of or low FMS usage. Inland explained that it chose to use the EOR option instead of FMS because it had developed comfort using that option and because EOR also gives families the flexibility to choose their own respite workers. San Diego indicated that it uses the EOR model to provide families the option to choose a respite worker and added that it believes EOR works better than FMS because the vendor handles the task of employing the respite worker. The deputy director of administration acknowledged that the two options have some differences, including that some respite workers may find the process for being hired by a vendor using the EOR option more burdensome. However, DDS's data limitations prevent it and others from determining the number of families actually using the EOR option and assessing its value. When regional centers do not offer FMS, they are depriving families of an option that may better suit their needs. Thus, DDS should ensure that families are sufficiently informed about and have sufficient access to all services, including the FMS option.

Please refer to the section beginning on page 3 to find the recommendations that we have made as a result of these audit findings.

We conducted this performance audit in accordance with generally accepted government auditing standards and under the authority vested in the California State Auditor by Government Code section 8543 et seq. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on the audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

Respectfully submitted,

MICHAEL S. TILDEN, CPA
Acting California State Auditor

August 30, 2022

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Appendix

Scope and Methodology

The Joint Legislative Audit Committee (audit committee) directed the California State Auditor to conduct an audit of DDS's oversight of the in-home respite program. Specifically, the audit committee requested that we review whether the regional centers authorize in-home respite services in compliance with law, whether families experience barriers to accessing those services, and the reasons for the low utilization rate of the FMS delivery option. The table below lists the objectives that the audit committee approved and the methods we used to address them.

Audit Objectives and the Methods Used to Address Them

	AUDIT OBJECTIVE	METHOD
1	Review and evaluate the laws, rules, and regulations significant to the audit objectives.	Reviewed laws, regulations, and other background material related to the in-home respite services program in California.
2	Select two regional centers each with at least 25,000 consumers and two regional centers each with approximately 1,000 consumers who receive participant-directed respite services and do the following:	Using DDS consumer data, judgmentally selected two regional centers—Inland and San Diego—with at least 25,000 consumers as of October 2021 to review. Judgmentally selected two regional centers—Golden Gate and San Andreas—with about 1,000 consumers who received participant-directed (FMS) in-home respite services in fiscal year 2020–21 to review.
	a. Determine whether the regional centers comply with the laws, rules, and regulations that govern service authorization for in-home respite services.	Interviewed staff at each of the four regional centers regarding their processes for authorizing in-home respite services. For fiscal years 2017–18 through 2021–22, reviewed five client files for in-home respite authorizations at each of the four regional centers to determine whether they complied with key in-home respite service authorization requirements.
	b. Determine whether regional centers apply monthly or quarterly limits on in-home respite service authorization.	• Reviewed policies and procedures and interviewed staff at each of the four regional centers to assess whether they impose limits on the authorization of in-home respite services. • Reviewed documentation to determine whether DDS approved any policies that describe setting limits on authorized hours for in-home respite services. • Reviewed appeals records and authorization files at the four regional centers and statewide data to determine whether, in practice, the centers are imposing limits to the number of in-home respite hours they authorize for families. • Surveyed more than 17,500 English-speaking families and more than 4,600 non-English speaking families (Cantonese, Mandarin, Spanish, and Vietnamese) who had valid email addresses served by the four regional centers that we reviewed. We received responses from about 3,600 families. We asked questions regarding whether they receive sufficient authorization of in-home respite services and whether regional centers have imposed limits on the number of authorized in-home respite service hours.

continued on next page . . .

	AUDIT OBJECTIVE	METHOD
	c. Determine whether there are barriers to consumers' use of authorized in-home respite services.	• For fiscal years 2017–18 through 2021–22, reviewed the following: – Relevant DDS documentation to determine whether DDS ensured that regional centers complied with state law to consult with stakeholders and develop plans to promote equity and reduce disparities in the use of in-home respite services. – The four regional centers' annual reports to DDS showing that they consult with stakeholders and what actions they plan to take to reduce disparities in consumers' use of regional center services. Interviewed regional center staff regarding their ongoing processes to identify and address barriers. – Appeals from consumers about in-home respite services to determine whether the four regional centers have adequate processes to discover and address concerns by consumers regarding in-home respite services or barriers to using in-home respite services. • Used our survey of families to determine whether they have experienced barriers to using in-home respite services.
	d. Determine whether there is a disparity among regional centers in service authorization and usage based on consumers' race, ethnicity, primary language spoken, age, diagnosis, residence type, and service delivery mode.	• Reviewed statewide demographic data to identify any disparities among regional centers related to in-home respite service authorizations based on any of the factors described in this objective or the three service delivery options. Analyzed the usage rates for each of the three service delivery options by demographic category—race, ethnicity, primary language spoken, age, diagnosis, and residence type—and by regional center. • For those categories where we identified trends, interviewed staff at DDS regarding significant disparities and included the results of this analysis in the report sections on barriers and FMS usage. We used the median value when comparing respite care usage, which represents the middle value of a category's respite care usage. This measure indicates that half of the consumers in the category use less than the median amount of respite and half of the consumers use more than the median amount. We include information about most of the demographic categories on our interactive dashboard on our website at http://www.auditor.ca.gov/reports/2021-120/supplementalgraphics.html. However, because we did not find any noteworthy trends related to residence type, we did not include this category on our dashboard or discuss it in the report. • Reviewed relevant DDS documentation such as stakeholder consultation meeting minutes to determine whether and how DDS reduces disparities and promotes equity in the delivery of in-home respite services. • Reviewed relevant documentation from each of the four regional centers to determine whether and how they consult with stakeholders to reduce disparities and promote equity in the delivery of in-home respite services, as required by state law.
	e. To the extent applicable and possible, identify the reasons for the low utilization rate of the FMS service delivery model.	• Reviewed outreach materials to determine whether DDS and the four regional centers had adequate processes to inform consumers about FMS, including whether they had a policy to perform outreach at regular intervals, used multiple mechanisms to do so, and ensured that the materials included sufficient information about the benefits of FMS to help consumers make informed decisions about using it. Interviewed staff at DDS and each of the four regional centers regarding reasons for any differences in utilization rates of the three service options. • Used our survey of families to ask whether and why they do, or do not, use the FMS service delivery option.
3	Evaluate the benefits of the FMS model and provide recommendations to improve the delivery of in-home respite services.	Documented reimbursement rates for in-home respite services under each service delivery option. Interviewed staff at DDS and at the four regional centers and reviewed relevant documents to identify the benefits of each of the service delivery options. Developed recommendations for improving the delivery of in-home respite services.
4	Review and assess any other issues that are significant to the audit.	None identified.

Source: Audit workpapers.

Assessment of Data Reliability

The U.S. Government Accountability Office, whose standards we are statutorily obligated to follow, requires us to assess the sufficiency and appropriateness of computer-processed information that we use to materially support our findings, conclusions, or recommendations. In performing this audit, we relied on electronic data related to in-home respite service usage and consumer demographics that we obtained from DDS. To evaluate the data, we reviewed existing information about the data, interviewed DDS staff members knowledgeable about the data, and performed electronic testing of the data. We found the data to be of undetermined reliability for our purposes. Although this determination may affect the precision of the numbers we present, there is sufficient evidence in total to support our findings, conclusions, and recommendations.

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STATE OF CALIFORNIA--HEALTH AND HUMAN SERVICES AGENCY GAVIN NEWSOM, Governor

DEPARTMENT OF DEVELOPMENTAL SERVICES
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August 5, 2022

Michael S. Tilden*
Acting California State Auditor
621 Capitol Mall, Suite 1200
Sacramento, CA 95814

Dear Mr. Tilden:

The California Department of Developmental Services (DDS or Department) has reviewed the California State Auditor's (CSA) draft report entitled "In-Home Respite Services: *The Department of Developmental Services Has Not Adequately Reduced Barriers to Some Families' Use of In-Home Respite Services.*" DDS appreciates the opportunity to respond to the draft report and provide comments on the audit results and assessment of the recommendations.

DDS recognizes the importance of respite services to individuals with intellectual and developmental disabilities, providing critical relief to family members that impacts relationships and wellness within the family. DDS is committed to continuous improvement in increasing access to services and reducing disparities where they exist.

DDS appreciates the collective work of the CSA auditors, Golden Gate Regional Center (GGRC), Inland Regional Center (IRC), San Andreas Regional Center (SARC) and San Diego Regional Center (SDRC) representatives to review the In-Home Respite Services program throughout this process.

DDS sees the audit process as an opportunity to identify areas for improvement that advance the use of in-home respite services throughout the developmental services system. Given the complexities of the developmental services system, DDS provided technical clarification regarding details in the draft report. We are pleased that CSA representatives have agreed to take the Department's input under consideration while finalizing the audit report.

The report included five recommendations specific to DDS, to which DDS offers a modified path toward achieving comparable outcomes.

Recommendations

1) *DDS should update its in-home respite data by January 2023 to periodically track the amount of respite hours authorized and used by each regional center, and the usage of each service delivery option (Agency, EOR, or FMS).* ①

* California State Auditor's comments begin on page 45.

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a) *DDS should use this information and the data it already collects from the regional centers to identify trends and disparities related to in-home respite services.*
b) *DDS should, at a minimum, analyze the usage of and authorization for in-home respite services across the demographic categories we list in the report. That analysis should identify any disparities statewide, at individual regional centers, or among regional centers.*
c) *If DDS identifies problematic disparities, such as low usage among individuals who speak languages other than English that suggest barriers to the use of in-home respite services, then it should take action to address them. For example, DDS should direct regional centers with low FMS usage to conduct additional outreach to ensure that families are aware of the benefits of this option.*

DDS comment:

The report states "DDS has not taken critical steps to address disparities in the use of in-home respite services." However, the findings are centered around barriers
② that are in line with the national workforce experience. DDS notes that service authorization and utilization data can be used to identify potential and actual disparities, and DDS continues to use both for that purpose, as explained below.

With service access and equity among its highest priorities, DDS has been examining service utilization data and consumer demographics for many years in all
③ service types including in-home respite services. The audit findings did not identify any disparities among consumer demographics and service utilization of respite services. The respite service expenditure data from FY 2016-17 through FY 2020-21 shows increasing trends in per capita expenditures across all ethnic and language groups:

Per Capita Expenditures for All Ages					
Ethnicity	**FY16/17**	**FY17/18**	**FY18/19**	**FY19/20**	**FY20/21**
Hispanic	$3,917	$4,150	$4,757	$5,932	$8,161
African American	$3,464	$3,711	$4,407	$5,519	$7,730
Asian	$3,732	$3,866	$4,349	$5,048	$6,743
White	$3,473	$3,644	$4,128	$4,717	$5,964
Other	$3,245	$3,396	$3,881	$4,562	$5,793
Totals:	**$3,664**	**$3,863**	**$4,418**	**$5,330**	**$7,140**

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Per Capita Expenditures for All Ages					
Language	**FY16/17**	**FY17/18**	**FY18/19**	**FY19/20**	**FY20/21**
Vietnamese	$4,556	$4,755	$5,126	$6,068	$8,939
Spanish	$4,146	$4,421	$5,067	$6,396	$8,734
All other languages	$4,071	$4,055	$4,664	$5,795	$7,637
Mandarin Chinese	$4,130	$4,261	$4,528	$5,310	$6,840
Cantonese Chinese	$4,009	$4,198	$4,970	$5,710	$6,645
English	$3,476	$3,661	$4,188	$4,961	$6,585
Totals:	**$3,664**	**$3,863**	**$4,418**	**$5,330**	**$7,140**

DDS' ongoing analysis of service utilization and consumer demographics has been foundational for the identification of issues with service access and equity impacting the developmental services system. Supported by compelling data, DDS has implemented its Service Access and Equity Grant Program since 2016, responding to the needs of targeted populations. The grant program led to the 2021 launch of a statewide Community Navigator Program to cultivate local assistance to families that is responsive to their cultural and linguistic preferences. Additional initiatives are increasing resources to regional centers such as enhanced service coordination for individuals with low or no purchase of services and funding for language access and cultural competency plans, furthering DDS' continued efforts to address identified trends and disparities. ④

- **Partially Agree.** The Department agrees with and already implements sub-recommendations (a), (b), and (c). Specific to sub-recommendation (c), DDS' proposal for the 2021 State Budget was enacted to include funding for enhanced service coordination for individuals with low or no purchase of services, among a number of other initiatives that address or prevent disparities in developmental services. The current data systems used by DDS and the regional centers are not designed to track authorized and utilized hours, nor each of the service delivery options. DDS currently uses financial authorization and expenditure data for the analyses described in the recommendations. The Budget Act of 2021 authorized development of a new uniform fiscal system (UFS) and a statewide consumer electronic record management system (CERMS) with implementation anticipated in Fiscal Year 2025-26. The specifications for these systems are being determined through extensive stakeholder engagement, and DDS will consider including the ability to track hours of service and service delivery option as capabilities to these systems.

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③ DDS believes its practice of monitoring expenditures allows trend analysis on actual utilization and therefore provides superior insight as to whether there are disparities in accessing the services across regional centers and consumer demographics. DDS agrees that service utilization data and consumer demographics should continue to be closely monitored and actions should be taken to address issues that emerge.

2) *DDS should review the policies of all 21 regional centers by October 2022 to ensure that they do not contain provisions imposing overall limits on the amount of in-home respite service hours authorized for families to receive each quarter and require revisions as necessary.*

- **Partially Agree.** By October 2022, DDS will review the policies of all 21 regional centers to ensure that they do not contain provisions that impose ⑤ overall limits and will require revisions as necessary. However, as in the case of the GGRC policy, DDS can approve policies that indicate a limit on the amount of in-home respite service hours provided there is a timely process for the regional center to allow exceptions to authorize additional hours when needed to meet an individual's needs. Consistent with Welfare and Institutions Code section 4620.3 and the case of *Williams v. Macomber*, regional center policies do not stand alone and must be balanced by review and consideration of each individual's needs and circumstances.

① 3) *DDS should develop standard outreach materials by October 2022 that present key information about each respite service delivery option, including a description of each option and its benefits and drawbacks. It should provide these outreach materials in multiple languages on its website and to all regional centers to include on their websites and disseminate to all of the families that use the center's services so they have the knowledge and opportunity to select the option that best fits their needs.*

DDS comment:

DDS conducted outreach activities relative to Participant-Directed Services (PDS), including in-home respite services with a Financial Management Services (FMS) agency. In recognition of the advantages of PDS for consumers and families, DDS expanded the types of eligible services in March 2020 as a flexibility during the COVID-19 pandemic and currently has regulations in process to continue their availability. In October 2020, DDS posted Frequently Asked Questions about PDS

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on its website, translated in multiple languages. In November 2020, DDS held several virtual informational sessions for consumers and family members about PDS, reviewing the aspects that may be beneficial for families, which services are eligible, how the funding works, and steps to take if they are interested in using PDS. These virtual sessions were open to the public, interactive and translated in multiple languages, with one session presented in Spanish, and one session specifically for regional centers. The materials and a recording are available on the DDS website.

- **Agree.** By February 2023, DDS will develop or modify existing outreach materials regarding options for respite services and considerations for consumers and family members. These materials will be available in multiple languages on DDS' and regional centers' websites and made available to regional center consumers and family members.

4) *DDS should amend its contract with the 21 regional centers by October 2022 to require all regional centers to have a plan for ensuring that they have an adequate number of service providers for all in-home respite service delivery options, including the FMS option.* ①

DDS comment:

The challenges family members reported regarding difficulty finding qualified and reliable respite workers are consistent with the national workforce shortage that spans multiple service sectors. The Budget Act of 2021 includes initiatives that support service provider capacity, including in-home respite services. Implementation of the service provider rate study, development of bilingual pay differentials for direct service workers, and a tiered training program tied to wage differentials for direct service workers are advancing systemwide efforts to stabilize the workforce and increase service provider capacity. Additionally, with the enactment of the Budget Act of 2022, a workforce stability initiative is establishing training stipends and an internship program to support direct service worker recruitment and orientation to developmental service delivery.

- **Partially Agree.** While service provider capacity is crucial to providing access to services, as noted above, the efforts and actions currently underway to address workforce challenges far exceed the reach of regional centers to manage and/or implement alone. CSA identified one regional center report of a shortage of FMS providers, which are ⑥

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necessary to support the delivery of PDS as well as the Self-
⑦ Determination Program. In lieu of modifying regional center contracts, DDS will include the development of FMS providers as a priority for the upcoming Community Resource Development Plans which are prepared by regional centers each fiscal year.

① 5) *DDS should amend its contracts with the 21 regional centers by October 2022 to direct them to train their service coordinators to explain the benefits of each of the in-home respite service delivery options so that families can determine which option will work best for them.*

⑦ ➢ **Partially Agree.** DDS agrees that more regional center expertise in PDS is beneficial to consumers and families. As authorized in the Budget Act of 2021, since our November 2021 directive, regional centers have been hiring Participant Choice Specialists as resources fully dedicated to supporting service coordinators, assisting consumers and families with transitions to PDS options, and building regional center institutional knowledge regarding PDS options, including in-home respite. Participant Choice Specialists are responsible for training service coordinators and for developing outreach and training plans to increase stakeholder awareness of PDS options. DDS will continue to work with regional centers and their Participant Choice Specialists.

On behalf of DDS, I would like to thank the CSA's Office for its extensive evaluation of In-Home Respite Services. The recommendations offered in the audit report have provided a valuable opportunity to reflect on our ongoing efforts to deliver upon the promises of the Lanterman Act.

Sincerely,

NANCY BARGMANN
Director

COMMENTS

CALIFORNIA STATE AUDITOR'S COMMENTS ON THE RESPONSE FROM THE DEPARTMENT OF DEVELOPMENTAL SERVICES

To provide clarity and perspective, we are commenting on the response to the audit from DDS. The numbers below correspond to the numbers we have placed in the margin of the response.

As is our standard practice, we communicated with DDS while it was reviewing our draft report to discuss any concerns it may have about the report. During these conversations, we informed DDS that we would change the implementation date for some recommendations and make other minor edits to some recommendations. Our recommendations start on page 3. (1)

DDS overstates its use of authorization and utilization data to identify disparities and barriers. As we note on page 19, DDS has not analyzed the data in a way that would allow it to identify various disparities, such as comparing the usage of and authorization for in-home respite services across demographic categories. By not performing such an analysis, DDS is limiting its ability to identify and address disparities in the use of respite services. (2)

As we discuss starting on page 18, our review of DDS data revealed some disparities in consumers' use of in-home respite services, including disparities related to age and diagnosis. Further, the expenditure analysis that DDS presents in its response is similar to an analysis it provided to us during the audit, neither of which provides sufficient detail to identify disparities in respite use. Specifically, the analysis does not include the amount of respite services families were authorized to receive, as we recommend, thereby inhibiting the ability to assess whether families and consumers are experiencing barriers that prevent them from using the full amount of these services. (3)

DDS has been unable to substantiate the efforts it describes to address disparities. As we explain on page 17, DDS did not provide documented examples of comprehensive analyses to demonstrate how these efforts reduced disparities. We look forward to reviewing DDS' efforts to improve its data collection as part of our audit follow-up process. (4)

We disagree with DDS's practice of approving policies that specify a limit on the amount of in-home respite hours as long as there is an exceptions process to authorize additional hours. Although we acknowledge that case law and statute require review and (5)

consideration of each individual's needs and circumstances, we state on page 22 that, because the Legislature removed hourly caps, policies that reference limits on respite hours are inconsistent with the intent of the Legislature and risk creating the impression among consumers, families, and regional center staff that an hourly cap is still in place. Moreover, such policies create additional barriers to families accessing respite services by imposing an hour limit and requiring a family to seek an exception. Thus, we stand by our conclusion that an exceptions process is not sufficient to comply with the Legislature's intent in repealing the hourly cap.

6 DDS mischaracterizes our finding related to the FMS option by stating that we identified only one regional center report of a shortage of FMS providers. In fact, we found that two of the four regional centers we reviewed did not have a vendor to provide FMS services, as we discuss on page 31. Further, as Figure 11 on page 30 shows, 13 of the 21 regional centers in the State have minimal usage of the FMS option.

7 Although DDS's response describes efforts that it will undertake to train service coordinators and develop outreach plans, we discuss starting on page 29 that DDS and many regional centers have not taken adequate action to ensure that the FMS option is available to families. Accordingly, we stand by our recommendation that DDS should amend its contracts with the regional centers to ensure that they have an adequate number of service providers for all in-home respite delivery options and train service coordinators to explain the benefits of each option to families. Formalizing such requirements would reinforce expectations among DDS and the regional centers.